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Social networks and health practices: influence of a diabetes online community on adherence to treatment

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Abstract *This study aims to understand how online communities can contribute to increasing the adherence of chronic patients to the treatment prescribed by the physician in Brazil. For this purpose, we applied the netnography method to analyze the community Diabetes: vivendo e aprendendo – troca de informações (free translation: "Diabetes: living and learning – information exchange"), considering the dimensions of adherence proposed by the World Health Organization (WHO) as a theoretical framework. The analysis shows the influence of cyberculture on health and disease processes, resulting in changes in physician-patient relationships, patient empowerment, and individual management of own chronic condition. The results also showed a positive influence of the interactions established in the community on the multidimensional factors of the adherence model proposed by the WHO1, also leading to the possibility of including a sixth related to connectivity. The primary motivations identified for community participation were access to information on the disease and treatment, the sharing of experiences and social support. Thus, the proposition of health policies that help chronic patients meet these needs tends to contribute to increased adherence to treatment.*

Key words *Online community, Adherence to treatment, Chronic disease, Diabetes, Health governance*

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Introduction

The changes that information and communication technologies have made in the way of conceiving health and disease processes, in the doctor-patient relationship, how patients address the disease, in the role of the patient in the self-management of own illness and in the patients' new ways of socializing with other patients and with the health system[1-4] are evident.

Moreira and Pestana[5] emphasize that online patient communities contribute to the promotion of greater health literacy and are "the new era of empowerment of patients and a patient-centered health system". The empowerment process can contribute to the re-signification of the natural social relationships among the stakeholders of the health system, allowing for a review of roles and meanings, and for greater citizenship in health, with greater social and political participation of patients[6]. This phenomenon is part of the broader context of possibilities for the Internet to enhance participation, interactive communication, civic engagement, information provision and democratization[7].

In this scenario, it is critical to understand to what extent the engagement of individuals with chronic diseases in virtual environments can positively influence adherence, since one of the main gaps in the treatment of chronic patients is the lack of adherence to treatment[8]. Therefore, this study aims to understand *how online health communities can influence adherence to the treatment of chronic patients in Brazil*. More specifically, we aim to (i) identify the factors that affect adherence of patients with chronic diseases, especially people with diabetes, to the treatment prescribed by the physician; (ii) understand what people with diabetes are seeking when engaging in an online health community; and, based on this understanding, (iii) identify the health system's opportunities for action to increase adherence of these patients to treatment. Thus, netnography method was adopted, analyzing for two months the community *Diabetes: living and learning – Information exchange*. (*free translation from the Portuguese*)

In this study, adherence is understood as a complex construct, influenced by multiple factors, following the definition of the World Health Organization (WHO)[9]. The WHO approach was chosen because this institution dominates the setting of global health governance[10] and because its multidimensional approach takes into account the patient and the entire cultural, social and economic context that surrounds it and shows better adherence results compared with one-dimensional approaches[11].

The study sheds light on two crucial current themes: (1) adherence of chronic patients to the treatment prescribed by the physician, considering the high prevalence of chronic diseases and the association with a high mortality rate[12]; and (2) social networks and health practices, more specifically the sharing of health information and experiences in online communities and the possible effects on adherence and participation in health.

In discussing these two challenging themes, the study brings contributions to the health system, identifying possibilities for action to increase chronic patient adherence to treatment, and for generating reflections on the importance of empowering patients to re-signify social relationships and building more equitable relationships, leaving as a stimulus to online health communities the organization and engagement towards the third level of empowerment – structural – for insertion into social and political projects[6]. For the academy, it may be noted that the study contributes to the construction of knowledge both on adherence to the treatment of chronic patients and the relationship between adherence, online health communities and social participation in health.

Theoretical references

Social Networks and Health Practices

In contemporary culture, changes in the way individuals seek health information[13], in the relationship between patients and health professionals[3] and social interactions regarding health problems and experiences are becoming increasingly evident[14]. These changes are shown by the new socializing methods and possibilities provided by new technologies, a phenomenon called Cyberculture[1].

The changes promoted by cyberculture in health are significant, especially regarding chronic diseases[14,15]. A progressive increased Internet use by chronic patients is observed, in numbers that are more significant than by any other patients[15], both concerning search for information and sharing knowledge acquired online with other people, in the so-called online communities, which can be defined as a social unit based on an internet platform that gathers individuals with

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similar interests and objectives who wish to build collective activities related to health care and education[16].

Thus, the figure of the expert patient, one who actively seeks information online about own health, treatment, symptoms, and costs[4] emerges. Search is not restricted to medical information or from specialized knowledge; it also includes reports, opinions, and knowledge of individuals with similar problems or experiences, who exchange information on blogs, discussion forums or virtual communities[17]. These patients become "experience experts", produce knowledge and want to have a voice in all aspects related to their diseases[3].

In a survey conducted in Brazil, Moretti et al.[13] found that for 86% of respondents, the Internet is the primary source of health information, a higher percentage than among physicians or specialists (74%). Similarly, Honorato[1], when reviewing studies on the interconnection between health and cyberculture, highlights the use of the Internet to obtain data and, besides this, its potential for publication and dissemination of information.

Several studies that correlate the use of online health platforms with the management of chronic diseases reveal that the interactions established in the virtual environment contribute to (i) greater knowledge of the patient about the disease, by sharing experiences in disease management or information searched on other sites[5]; (ii) better self-management of the chronic condition, attributed to the exchange of experiences, counseling and the similarity of problems and feelings[18]; and (iii) greater social support, through positive reinforcement, counseling and the sharing of information and experiences[19]. In fact, communities and online discussion forum? have been shown as open space for individuals with chronic diseases to exchange information about disease management and social support[15].

Peer support leads to the empowerment of patients by building and strengthening the network of relationships, acceptance, and feeling of belonging to the community[19]. Concerning support and social networks, Canesqui and Barsaglini[20] highlight positive effects "on behavior, adjustment and management of chronic diseases; in the relationships of the sick with the services and health professionals; in the adherence to treatments, improved quality of life, adoption of new lifestyles and disease risks prevention [...]". Empowerment is understood here as a process of mobilization and practices that aim to drive individuals and groups to strive for better living conditions, to become active individuals and groups who demand increased power, autonomy and participation in interpersonal and institutional relationships[6].

Adherence to treatment of chronic diseases and online communities

WHO defines adherence as "the extent to which a person's behavior – taking medication, following a diet and/or executing lifestyle changes – corresponds with agreed recommendations from a health care provider"[9]. Since the 1970s, several studies have been produced on the subject of adherence, given its high complexity and primacy in determining the effectiveness of treatment[9]. Throughout studies produced on the theme and the different assumptions adopted, two approaches stand out[21]: those that focus on the patient as the sole responsible for adherence; and those who understand that adherence is affected by other factors, such as the patient's own social and cultural environment.

Following a holistic approach, WHO emphasizes that focusing exclusively on patient-related elements tends to neglect essential factors of adherence. To cover multiple factors and facilitate understanding of the complex phenomenon, WHO[9] highlights five factors that affect adherence: (i) the patient; (ii) the treatment; (iii) the disease; (iv) the socioeconomic aspects; and (v) the health system. The main items that underpin each factor are shown in Chart 1.

Focusing on the online environment, we note that chronic patients using online communication tools tend to become more experienced, feel more socially supported and empowered, and achieve better behavioral and clinical outcomes compared to patients who do not use such tools[14].

Despite the high potential of online resources to promote rapid communication and interaction among different health stakeholders, many agents (physicians, administrators, academic institutions, among others) are unaware of the relevance of social media and its potential application in daily activities and adherence to prescribed treatments. As a consequence, many professionals refrain from a proactive stance in online social interactions and reject the discussions fostered by them[2].

Concerning this point, Bustamante[3] emphasizes that as doctors seek out communities, they can better understand patients' psychology, their difficulties and feelings, and thus identify better

Chart 1. Dimensions of adherence to long-term treatments.

Factor	Items
Patient	Knowledge, attitudes, beliefs, perceptions and expectations of the individual; psychosocial stress; low motivation; inadequate knowledge and skills in symptom management and disease management; low perception of the need for treatment; little perceived effect and negative beliefs about treatment; misunderstanding and non-acceptance of the disease; disbelief in diagnosis; low perception of disease risk; misunderstanding of treatment instructions; low expectations regarding therapy; frustrating experiences with health professionals; feelings of stigma due to disease.
Treatment	Length of treatment; previous treatment failures; frequent changes in therapy; side effects of treatment and availability of medical support to address them.
Disease	Severity of symptoms; severity and disease development; level of disability (physical, psychological, social and professional).
Socioeconomic	Poverty; low level of education; unemployment; illiteracy; lack of effective social support networks; unstable living conditions; long distance treatment center; high cost of transportation and medication; culture and beliefs about disease and treatment; dysfunctional family.
Health System	Poor drug distribution systems; lack of knowledge and training of health professionals for the management of chronic diseases; overwork of health professionals; quick consultations; low system capacity to educate patients; inability to establish community support and capacity for self-management; lack of knowledge about adherence and effective interventions to improve it.

Source: Adapted from the World Health Organization[1].

ways to make them allies in the treatment process. Also, van der Eijk et al.[14] believe that the growth of interactive digital technologies and the appropriation by the field of health have expanded the possibilities of communication beyond a tight schedule of face-to-face medical consultations and, thus, health professionals must accept patients as partners or the health system will be vulnerable to a massive loss of confidence.

In short, addressing the complex issue of adherence and its challenges requires thinking about the idea of stakeholder-based governance, with democratic forms of public-private and citizen participation in decision-making processes, thus increasing the level of interaction between the different social stakeholders. The growth of interactive governance methods is compatible with the dynamics of contemporary culture, in which the influence of a greater plurality of stakeholders is observed, as well as the more significant interaction between different social representations[22]. According to Bahia[23], "health is a social good that requires a democratized access to the whole collection of knowledge, technologies, and experiences, as well as the participation of the popular classes in the definition of health-related needs and aspirations."

Methods

Netnography was chosen in this study as a method of observing social practices in the online environment. The term coined by Kozinets[24] adapts the ethnographic method for the study of cultures and communities in the digital environment. Netnography is characterized by (i) the majority analysis of public texts; (ii) a posteriori analysis, based on the communications' files saved in the virtual environment; (iii) observation of interactions between people – and not of individuals separately; and (iv) analysis of a peculiar form of interaction that unfolds in the public space[25].

The study followed the steps described by Kozinets[24]: (a) preparation for entry into the field; (b) data collection; and (c) data interpretation and analysis.

a) Preparation for entry into the field - formulation of research questions, based on the structuring of the social practices observation script, and identification of the online community to be analyzed.

The community selection took into account the five aspects highlighted by Kozinets[24]: a focused approach to the relevant research questions; high post traffic; a high number of messag-

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es posted; rich and detailed data; and high interaction among members. Initially, a community mapping was carried out using search engines, using the terms "chronic disease", "community" and the names of the main chronic diseases: diabetes, cancer, hypertension, heart diseases, and so forth. Five potential research niches were identified: two blogs and three discussion groups on Facebook. After the observation of each vehicle for two weeks and a comparative analysis based on the Kozinets' criteria[24], the community was selected: *Diabetes: Vivendo e Aprendendo – Troca de informações* (Free translation: "Diabetes: Living and Learning: Exchange of information"). The option to analyze the online community with a focus on diabetes is also justified by the fact that this disease is one of the four leading causes of deaths due to chronic disease in Brazil[26], that there is a shortage of studies on the adherence of diabetic patients in developing countries and of WHO's prognosis that, in 2025, the highest prevalence of this disease will occur in those countries[9].

b) Data collection - After familiarizing with the community, data collection was carried out for a period of two months (January 26, 2015 to March 26, 2015), which included the reports of the participants and the researchers' notes. Information about the profile of the active members of the community was also collected, aiming to identify the relationship with the disease (patients or friends/relatives of diabetics), gender and the state in which they lived.

c) Data interpretation and analysis - Data were compiled and categorized from the five adherence dimensions proposed by the WHO[9]. Concerning data interpretation, the posts and their respective comments were re-read, correlating the elements searched and found by the users in the network with the dimensions of adherence.

Regarding the ethical aspects of the study, the prerogative of Langer and Beckman[27] was adopted, which proposes, for the analysis of communities open to the public, the use of the ethical criteria of content analysis of public texts. Following the authors' understanding, since the community selected in the study is an open group of Facebook and the content of the analyzed posts was publicly available from the authors, there would be no need to request authorization for the collection and direct citation of the data. Also, it is believed that the non-manifestation of the researcher in the community prevented weakening the content posted by the users' fear of being observed[27]. Such a practice is called lurking and is typical of digital media research, where researchers only observe the behavior of community members. However, this procedure is not devoid of criticism, since some researchers argue that lurking can be in fact considered as participation, a condition necessary for ethnographic practices[28].

Results and analyses

Profile of the analyzed community

The community was created in January 2015 by a Type-1 diabetes patient, with the description: "Caring for your diabetes has never been easier, even more exchanging information with those who better understand the subject... We diabetics." The description reinforces Bustamante's argument[3] about the conversion of patients into experience experts. Concerning the profile of active participants, whose information could be collected, the predominance of females, patients (other relatives, especially wives, mothers and daughters) and residents of the South and Southeast regions of the country was identified.

In total, 354 posts were recorded during the observed period, which generated 1,582 comments and 3,326 likes. The following pattern was observed in postings: 172 were dissemination of information (disease, treatment, and income); 72 thanked their reception in the group; 45 shared personal information (36 on treatment development, blood glucose measurements and visits, and 9 on prescriptions); 16 sought information; 15 were outbursts and/or request for help; 14 were motivating; 14 concerned the community itself; and 6 were invitations to offline events.

The creator of the community moderates the posted content by removing messages that are sad, shocking or violating the group's rules of conduct. The moderation of the tone of the posts is celebrated by many participants, as follows: "Thank you, that's right, always positive thoughts!". Motivational messages drive multiple responses and engage community members in a chain of positive comments.

Factors that affect adherence to treatment and what people with diabetes seek when participating in the online community

Patient-related factors *– psychosocial stress, poor motivation, inadequate knowledge and skills in symptom management and disease management, poor understanding of the disease, poor per-*

ception of disease risk, misunderstanding of treatment instructions, and frustrating experiences with health professionals.

Patients seek support and patient-participants provide guidance on the disease and its management, based on the knowledge gained from individual experience, health professionals and/or through sites' information, in line with previous studies[1,5] and with the understanding of Bustamante[3], on the experience expert patient, and Cunha et al.[7] on the provision and democratization of information through the internet. Although all posts analyzed have had a constant "prescription" of conduct, members invariably appeared alerting to the dangers of self-medication and the need to consult qualified health professionals. As for psychosocial factors, there was a widespread sharing of motivational messages, which characterize the social support identified in previous studies[15,19,20].

Treatment-related factors - *treatment complexity, frequent therapy changes, drug reactions (side effects), and lack of medical support to address them.*

A large volume of postings on diet and exercise were observed. Participants sought tips, published outbursts, frustrations, and also successful stories about behavioral change. In response, they received adequate diets, warnings against poor eating habits and incentives for physical exercise, in agreement with Canesqui and Barsaglini[20] and Merolli et al.[19]. Regarding the complicated treatment, some members reported changes made by physicians in their treatment, whether the type of medication or the dosages and the effects generated by these changes. In return, they found the sharing of personal information from other participants about treatment management and drug reactions. In this regard, it is possible to observe that other patients fulfill the scarce level of dialogue and guidance of health professionals[3] and that this fact reduces confidence in the health system[14] and is potentially dangerous. In some postings, for example, the information about personal experiences with medications was contradictory. However, one participant's recommendation for seeking medical advice was consistent.

Disease-related factors - *the severity of symptoms, the progression of disease and evaluation of treatment efficacy.*

It was observed that participants sought to exchange information about the *symptoms and demands of the disease*, contributing to the greater knowledge about the chronic disease, in line with Cunha et al.[7] and Honorato[1]. There was a mutual encouragement among community members in the *monitoring of the disease* with continuous measurements of glycaemia, in the warning of the dangers of a high glycemic index and the identification of similar *symptoms*. Besides, some members of the community were advised to go to the doctor, given the results of the measurement of glycaemia, as well as counseling to inform the symptoms to the doctor.

Socioeconomic factors - *social support, cost of treatment and transportation.*

Community participants are seeking information on devices, supplies, and foodstuffs suitable for people with diabetes with lower prices, as indicated by Garbin et al.[4]. In response, they find tips on places with cheaper products, and sometimes participants offer products through the post office – such a situation involves members who do not live in large urban centers and face difficulties in buying in their city. Information exchanges, as well as the delivery of products, are the plurality of stakeholders acting in a network – network-based governance[22] to fill social gaps and help in adherence to treatment. Concerning *social support*, messages of appreciation for reception in the community, sharing of outbursts and frustrations, invitations to face-to-face meetings, and holiday celebrations were observed[15,19]. In response, participants found reception, emotional support in times of discouragement, community moderation with the exclusion of negative messages and readiness to extend interactions beyond the virtual network.

Health system-related factors - *lack of knowledge and training of health professionals for the management of chronic diseases, low capacity of the system to educate patients, poor medicines and supplies distribution system and difficult access to resources.*

It was identified that information sought in the online community about the disease and treatment could/should be better clarified by a health professional, which points to the *lack of knowledge and training of health professionals for the management of chronic diseases*, as well as to the low capacity of the system to educate patients. Such a gap shows a paradox in the treatment of chronic patients: proactivity in self-management of the disease is expected, but patient participation in the process is neither encouraged nor supported. As a result, many chronic disease patients seek out online health communities to clarify concerns with more experienced patients in disease management[3]. Also, several participants

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requested information on the *medicines and supplies distribution system*, shared *difficulties in accessing resources* of the public or private health system, and sought to *exchange supplies* through the community. In response, participants found guidance on the access to supplies provided by the public health system and the availability of some members for the exchange of unused medications and supplies. It was also possible to observe the sharing of experience and the outburst of users with difficult access to the resources of the public or private health system, including access to medical care, and, in response, the incentive to adherence to treatment even in the setting of lack of access.

How can online health communities influence adherence to the treatment of chronic patients in Brazil?

Chart 2 summarizes the elements sought by the participants in the analyzed online community and the role it played.

Chart 2 shows that the results of the study indicate that online health communities are a powerful tool to address some of the challenges posed by adherence to the treatment of diabetes and, in general, chronic diseases.

In addition to the five dimensions of adherence proposed by WHO[9], the analysis of results suggests the possibility of coexistence of a sixth dimension, denominated *Connectivity* in this study, that is proper to the interactions established and provided by the virtual environment. By providing contact with individuals with similar chronic conditions, connectivity facilitates the recognition, acceptance and better management of the disease. From the relationship with other patients and by sharing similar experiences in disease management, individuals reinforce their identity of sick subjects, requiring specific intervention, and a sense of belonging to a group, contributing to increased acceptance of the disease and understanding of the need for treatment, thus contributing to increased adherence to therapy[19].

In the online universe, *connectivity* overlaps with the other dimensions proposed by WHO[9], mainly concerning the *socioeconomic* (social support) and the *patient* (motivational aspects and information about the disease and its management) dimensions. In fact, the main aspects of patient interactions in *online* communities are (i) social support – reception, outbursts, sharing of frustrations and motivational messages; and (ii) educational aspect – sharing knowledge about the disease and treatment, as well as experiences in the management of chronic disease. A singularity of these interactions in online patient communities is the fact that the information exchanged is not only from the relationship with doctors or specialized literature but also – and in no small extent – from individual experience with own chronic condition.

Several studies have identified social support as a result of interaction among patients in the virtual environment when they find mutual support between people with similar health conditions[15,19]. As in the studies found in the literature, the possibility of sharing experiences and establishing links that promote acceptance and a sense of belonging to a community[19] also appeared in this research as a crucial point of social support in the online environment, influencing adherence to therapy[9].

Concerning the search for information about the disease and its treatment in online health communities, several studies point to a relationship with gaps left by the health system in providing guidelines and support to chronic patients[18].

In this research, patients shared good and bad experiences with physicians while requesting recommendations from (or recommending) good practitioners. However, many professionals still do not know or prefer to ignore the influence of social networks on the empowerment of the chronic patients and their effect on doctor-patient relationship[2], hindering the discussion of the issue with their patients. Insofar as the online community has broad informational relevance for patients, contributing to greater knowledge about the disease and treatment, as well as for the exchange of (not only scientific but also popular) knowledge and individual experiences in self-management, it can contribute to the establishment of a new, less hierarchical doctor-patient relationship, since a more empowered patient with a differentiated knowledge deriving from own experience with the disease is evidenced[3].

The integrated participation of other stakeholders of the health system (health professionals, managers, academics) in online patient communities contributes to a better understanding of patients' longings, needs, motivations in the management of their chronic condition, as well as for better understanding of the experience and popular knowledge. The relationship with society is vital for more participatory, efficient and democratic governing ways, culminating in the

Chart 2. Summary of results.

Factor	What do participants seek in the online community?	Role played by the online community
Patient	- Information on the disease and its management - Treatment information - Exchange of information about the symptoms of the disease - Recommendations from good doctors	- Increased patient knowledge about the disease and its corresponding treatment (drugs, tests, diets), based on the knowledge acquired by the patients from the individual experience in the management of the disease, information obtained from websites or health professionals - Recommendations of health professionals - Sharing good and bad experiences with doctors - Psychosocial issues associated with motivational beliefs and messages - Encouraging adherence to treatment
Treatment	- Tips for following the prescribed behavioral change (diet and exercise) - Sharing difficulties in the adoption of behavioral change (publication of outbursts, frustrations) - Concerns about side effects resulting from changes in therapy	- Sharing (positive and negative) experiences on adherence to prescribed behavior change - Incentive for adherence to behavioral change (dietary recipes, warnings against bad eating habits, incentives for physical exercise, suggestion of establishing physical exercise practice groups) - Guidelines on treatment management - Exchange of experiences on side effects with medicines
Disease	- Information about the symptoms and demands of the disease - Information on blood glucose measurement	- Sharing information about the symptoms and demands of the disease - Greater knowledge of the patient about the disease - Guidelines and incentive for monitoring and control of the disease - Providing guidelines on blood glucose measurement - Alerts for the dangers of high glycemic index - Identification and sharing of similar symptoms - Personal assessment of treatment efficacy - Guidance for seeking health professionals - Encouraging adherence to treatment
Socioeconomic	- Information on devices, supplies and foodstuffs suitable for diabetics with lower prices, as well as sale outlets - To vent and share frustrations - Fate-to-face meetings	- Information that contributes to reduce the cost of treatment and transportation - Availability to send products - Reception - Social support - Moderation of the community excluding negative content - Availability to extend the conversation to other modalities online and/or offline - Encouraging adherence to treatment
Health System	- Search for information about the disease and treatment - Information on medicines and supplies distribution system - Sharing difficulties to access public and/or private health system resources - Exchange of supplies through the community	- Guidelines for obtaining supplies provided by the public health system - Availability to exchange medications and unused supplies - Encouraging adherence even in the scenario of lack of access

Source: Prepared by authors.

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proposal of policies with the collaboration of different social stakeholders, oriented by the perception of health as a social phenomenon, which must be understood in its breadth, considering social, cultural and environmental determinants[10]. The notion of governance, which can be defined as the way in which power is exercised, encompassing the structure and functioning of governments and society as a whole[10], thus seems useful in thinking about the challenges of adherence to the treatment of chronic patients for including not only governmental institutions but also informal social networks for a valid action in the search for solutions to this public problem.

From the results, some opportunities for health system performance are identified: (1) Online presence with the provision of information on corresponding diseases and treatment; (2) Online availability to clarify the primary concerns of patients; (3) Online platform support, consisting of patients, driving the sharing of inspiring experiences and stories; (4) Support from online platforms that encourage behavioral change required for treatment; (5) Training health professionals for patient adherence and education; (6) Raising the awareness of health professionals about the importance of the Internet and its diverse connectivity possibilities, which should be seen as an ally; (7) Incentive to patient self-management; (8) Analysis of the patient's socioeconomic context, identification of aspects to be overcome for full adherence to treatment and development of strategies to address the difficulties and meet treatment objectives; (9) Patient follow-up with continuous monitoring and re-evaluation of treatment.

These opportunities are in line with Bahia's[23] understanding about the need to democratize people's access to health knowledge, democratization of access to knowledge, insofar as the presence of different stakeholders in the online community can contribute to the exchange of technical-scientific and popular knowledge about health, and also about citizen participation in the definition of health needs and aspirations.

Conclusion

The research showed that there is a positive influence of the interactions established in the online health community on factors related to the five dimensions of adherence to chronic treatment, suggested by WHO – the primary specific objective of the research. Also, it was identified the possibility of including a sixth dimension, proper to the virtual environment, called *connectivity*. This dimension could contribute to the factors that increase adherence by providing recognition and acceptance of the disease, as well as social support.

Concerning the elements sought by chronic disease patients in an online health community – according to the second specific objective – the community analysis facilitated the fitting of results into three main categories: (i) access to information; (ii) sharing personal experiences of living with and managing the disease; and (iii) social support. Such information is of high relevance to guide actions of health systems to increase patient adherence.

Patients' demands are met by the online community and exceed initial expectations, when, for example, a participant's orientation goes beyond the question asked by the message interlocutor or when informative or motivational messages are posted spontaneously. We observed that patients who engage in online initiatives, such as the community in question, adopt a proactive attitude of self-management of the chronic condition. Such behavior is often driven by the gaps left by the health care system in the care and guidance of such patients.

As for the health system's opportunities to act in order to increase the adherence of chronic patients – third specific objective –, one can create public services that help patients meet the three main demands identified in this study (access to information, sharing of personal conviviality and disease management experiences, and social support), corroborating to the adherence to the treatment.

The netnographic method of observing and analyzing online communities can, at the same time, be considered a strength and a weakness of the study. The strength of the approach is the examination of online discourse among community members in their most organic way, without the influence of professionals or research tools. This is also a limitation as the data collected is restricted to what the participants choose to discuss and publicly disclose, and can thus be set as a partial form of ethnography. Another aspect that deserves attention is that netnography has sometimes been criticized for the lack of scientific rigor in the way data are collected and analyzed[29]. To overcome this possible weakness, in this study, the theoretical model proposed by the WHO was adopted as the theoretical framework for data collection and analysis. Again concerning data collection, another drawback of the research is

the subjectivity of the researchers in the analysis of the content, although one has eagerly sought objectivity in the process of interpreting data. Also, the fact that researchers did not introduce themselves to community members during data collection can raise criticism about active participation in the virtual environment. Finally, since this is qualitative research and analysis of a single community, findings are not generalizable.

Despite its possible weaknesses, the study contributes to the construction of knowledge about adherence to the treatment of chronic patients, especially diabetics, as well as on the relationship between adherence, online health communities and social participation in health in Brazil, a developing country, whose causes of adherence to medical treatment and the impact of social networks are still poorly studied and understood. Public managers argue that this study allows a greater understanding of the gaps left by the health system, which are opportunities for action by the public power, using cyberculture as an ally in increasing adherence of chronic patients to the treatment prescribed by the physician.

Future research can thus complement the results of this study by conducting surveys with participants from various virtual communities, as well as studying other online health communities, adopting as a data collection technique in-depth interviews, which would facilitate direct questions to participants about the experience in the online community. It is also possible to confront the findings of this study with investigations that explore the physician-patient relationship, mainly from the perspective of health professionals, regarding the phenomenon of online health communities and about the possibilities of creating services that increase adherence.

Collaborations

LS Fernandes worked on literature review, methods, data collection, and analysis. C Calado worked on literature review, data analysis, design and final drafting of the paper. CAS Araujo worked on the methodological orientation of the study, on the structuring and final drafting of the paper.

References

1. Honorato EJSA. A interface entre saúde pública e cibercultura. *Cien Saude Colet* 2014; 19(2):481-485.
2. Grajales III, FJ, Sheps S, Ho K, Novak-Lauscher H, Eysenbach G. Social media: A review and tutorial of applications in medicine and health care. *J Med Internet Res* 2014; 16(2):e13.
3. Bustamante J. Poder comunicativo, ecossistemas digitais e cidadania digital. In: Silveira AS, organizador. *Cidadania e redes digitais*. São Paulo: Comitê Gestor da Internet no Brasil, Maracá, Educação e Tecnologias; 2010
4. Garbin HBR, Pereira Neto AF, Guilam MCR. A internet, o paciente expert e a prática médica. *Interface (Botucatu)* 2008; 12(26):579-588.
5. Moreira PJ, Pestana SC. Saúde Web 2.0 e comunicação em saúde: A participação em comunidades virtuais em Portugal 2012. *Revista de Comunicación y Salud* 2012; 2(2):47-62.
6. Kleba ME, Wendausen A. Empoderamento: processo de fortalecimento dos sujeitos nos espaços de participação social e democratização política. *Saude Soc* 2009; 18(4):733-743.
7. Cunha MAVC, Coelho TR, Pozzebon M. Internet e participação: o caso do orçamento participativo digital de Belo Horizonte. *Rev Adm Empres* 2014; 54(3):296-308.
8. Carvalho ALM, Leopoldino RWD, Silva JEG, Cunha CP. Adesão ao tratamento medicamentoso em usuários cadastrados no Programa Hiperdia no município de Teresina (PI). *Cien Saude Colet* 2012; 17(7):1885-1892.
9. World Health Organization (WHO). *Adherence to long-term therapies: evidence for action*. Geneva: WHO; 2003
10. Buss P, Machado JMH, Magalhães DP, Setti AFF, Buss DF. Governança em saúde e ambiente para o desenvolvimento sustentável. *Cien Saude Colet* 2012; 17(6):1479-1491.
11. Roter DL, Hall JA, Merisca R, Nordstrom B, Cretin D, Svarstad B. Effectiveness of interventions to improve patient compliance: a meta-analysis. *Med Care* 1998; 36(8):1138-1161.
12. World Health Organization (WHO). *Integrated chronic disease prevention and control*. Geneva: WHO; 2016.
13. Moretti FA, Oliveira VE, Silva EMK. Acesso a informações de saúde na internet: Uma questão de saúde pública? *Rev Assoc Med Bras* 2012; 58(6):650-658.
14. van der Eijk M, Faber MJ, Aarts JW, Kremer JA, Munneke M, Bloem BR. Using online health communities to deliver patient-centered care to people with chronic conditions. *J Med Internet Res* 2013; 15(6):e115.
15. Stellefson M, Chaney B, Barry AE, Chavarria E, Tennant B, Walsh-Childers K, Sriram PS, Zagora J. Web 2.0 chronic disease self-management for older adults: a systematic review. *J Med Internet Res* 2013; 15(2):e35.
16. Demiris G. The diffusion of virtual communities in health care: concepts and challenges. *Patient Educ Couns* 2006; 62(2):178-188.
17. Gheorghe IR, Liao MN. Investigating Romanian Healthcare Consumer Behaviour in Online Communities: Qualitative Research on Negative eWOM. *Procedia - Social and Behavioral Sciences* 2012; 62:268-274.
18. Hewitt-Taylor J, Bond CS. What E-patients want from the doctor-patient relationship: Content analysis of posts on discussion boards. *J Med Internet Res* 2012; 14(6):e155.

19. Merolli M, Gray K, Martin-Sanchez F. Health outcomes and related effects of using social media in chronic disease management: A literature review and analysis of affordances. *J Biomed Inform* 2013; 46(6):957-969.
20. Canesqui AM, Barsaglini RA. Apoio social e saúde: pontos de vista das ciências sociais e humanas. *Cien Saude Colet* 2012; 17(5):1103-1114.
21. Leite SN, Vasconcellos MPC. Adesão à terapêutica medicamentosa: elementos para a discussão de conceitos e pressupostos adotados na literatura. *Cien Saude Colet* 2003; 8(3):775-782.
22. Gomides JE, Silva AC. O surgimento da expressão "governance", governança e governança ambiental. *Revista de Ciências Gerenciais* 2009, 13(18):177-194.
23. Bahia L. Entradas e bandeiras e o SUS no século XXI. *Cien Saude Colet* 2012; 17(11):2878-2880.
24. Kozinets RV. The field behind the screen: Using netnography for marketing research in online communities. *J Mark Res* 2002; 39(1):61-72.
25. Nimrod G. The fun culture in seniors' online communities. *Gerontologist* 2011; 51(2):226-237.
26. World Health Organization (WHO). *Noncommunicable Disease Country Profiles 2014*. Geneva: WHO; 2014.
27. Langer R, Beckman SC. Sensitive research topics: Netnography revisited. *Qualitative Market Research: An International Journal* 2005; 8(2):189-203.
28. Polivanov B. Etnografia virtual, netnografia ou apenas etnografia? Implicações dos conceitos. *Esferas* 2013*;* 2(3):61-71.
29. Rebs R. Reflexão epistemológica da pesquisa netnográfica. *Comunicologia* 2011; 8(1):74-102.

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